Children's Disabilities Workgroup Minutes

Meeting #4
September 27, 2011, 10:00 am to 3:15 pm
United Way of Central Iowa
1111 9th Street, Des Moines, IA 50314

MINUTES

Attendance

Workgroup Members: Jennifer Vermeer/Chair, Mark Peltan/Co-Chair, Marilyn Althoff, Gail Barber, Nicole Beaman, Paula Connelly, Julie Curry, Jim Ernst, Jerry Foxhoven, Jason Haglund, Jan Heikes, Janice Lane, Marilyn Lantz, Samantha Murphy, Rhonda Shouse, Jason Smith, Debra Waldron

Legislative Representation: None

Facilitator: Kappy Madenwald, Technical Assistance Collaborative (TAC)

DHS Staff: Don Gookin, Pam Alger, Joanna Schroeder, Laura Larkin, Carmen Davenport

Other Attendees:

Joan Discher	Magellan
Deborah Thompson	Legislative Services Agency (LSA)
Vickie Miene	CHRC, CCC
Sheila Hansen	CFPC
Bob Emley	Grand View University
David Basler	Childserve
Maria Walker	PCHS
Liz O'Hara	UI-CDD
Casey Westhoff	The ARC
Karen Bougher	Polk County Health Department Coalition
Mike Heller	Boystown
Paula Feltner	Orchard Place
Erick Oosteniak	Coalition
Kristen Oliver	

Agenda

Agenda Topics:

- Re-cap of Meeting #3: Review of Minutes
- 2010 Iowa Household Health Survey on Children's Mental Health
- Review of draft definition of a System of Care for Children and Families in Iowa
- Consolidated Outcomes – September 20, 2011 draft
- Core Services for Children (Continuation of discussion from 09/13/11)
- Agenda development for October 11, 2011 meeting

WORKGROUP OVERVIEW

Jennifer Vermeer opened the meeting asking for any comments on the minutes from the meeting held on 09/13/11. On Page 4 of the meeting minutes, one workgroup member asked that the word 'youth' be struck from the document, and replaced with 'very young children.' The matter was discussed and adopted by the workgroup.

Dr. Waldron presented highlights from the 2010 Iowa Child and Family Household Health Survey on children's mental health, more specifically related to behavioral and emotional health, special healthcare needs, and parenting stress. The data was gathered in fall 2010 and spring 2011, and included 2400 families. Parents were asked if there was any time in the past year when they or a health care provider thought their child had a need for behavioral or emotional care.[1] Dr. Waldron pointed out the following findings from the survey:

- Behavioral and emotional healthcare needs increase with age, with 15% of the children being between the ages of 15 – 17. Overall, about 68,000 children were reported to have had a need for behavioral and emotional health care in the past year. "Children with a need for this type of service were more likely to be older, have significant needs regarding behavioral/emotional issues, and have a primary parent who report having no one to turn to for parenting support, who experience higher levels of parenting stress and who have lower mental health status. Some specific findings:
    - 19% of the children had special healthcare needs.
    - 28% of parents reported having high stress due to parenting.
    - 14% of children with a need for behavioral/emotional care had a parent who fell into the category of 'poor mental health' on the parent mental health scale compared to 7% who did not.
    - Among parents reporting a need for behavioral and emotional help for their child about 11% reported that they did not have anyone they could turn to for day-to-day emotional help with raising children. This compares to 4% of parents who reported that their child did not need this type of care.

[1] ***Children's Behavioral and Emotional Health in Iowa: Results from the 2010 Iowa Child and Family Household Health Survey*, Policy Brief, The University of Iowa Public Policy Center, September, 2011**

Dr. Waldron pointed out the need to intervene early in the life of children to avoid increased problems as children age. This information gave the workgroup a springboard into identifying core services, which would include parent support.

Dr. Waldron also provided a handout to the workgroup with definitions of the following:

- Medical Home ~ Every one has a medical home; the Primary Care Provider (PCP) works in partnership with children and families medical and non-medical needs.
- Health Home ~ This expands on the Medical Home, and provides comprehensive services for individuals with chronic conditions; and
- Medical Neighborhood ~ Encompasses the services and supports from the medical home, community services, social service organizations, and state/local public health agencies.

Further discussion focused on the required reading of the workgroup. From the Child Welfare Issue Brief, "Supporting Parents with Mental Health Needs in Systems of Care, workgroup members commented on the need to be sensitive to families with mental health needs and to achieve better outcomes the system needs to do better planning for children and families. There is a need for family navigators to help families, and for families to have a voice. Problems get magnified when families do not have a voice and their emotions are not heard/validated by professionals. The article affirms what the workgroup has been doing.

It was pointed out that it is often difficult to see two journeys within the same household - the parent's journey and the child's journey. There is a need for professionals to value the parent's voice and choice, and to use family-centered plans. A workgroup member said, "The most essential thing (as a parent) is that I am being heard." Another workgroup member reminded us all that we must think about systems accessibility from a cultural perspective—Iowa is very diverse.

A series of articles focus on treatment of persons with co-occurring mental illness and developmental disability.

- Picking Up the Pieces of Our Own Mistakes: Supporting People with Co-Occurring Conditions
- Effective Community Services Systems for Individuals with Co-existing Developmental Disorder and Mental Illness
- Getting a Life: State Strategies for Supporting Individuals with Co-Existing Conditions

There was workgroup member concurrence that individuals with co-existing conditions and their families are not getting integrated care and are getting only partial support from a number of systems. There is a need to develop competencies to deal with co-occurring conditions.

The Practice Guidelines: Core Elements in Responding to Mental Health Crises published by SAMSHA highlighted the need to establish a solid foundation for a crisis system with values and principles similar to the System of Care. Ten essential values in

crisis intervention include avoiding harm, addressing trauma, use of shared responsibility and decision making, viewing the person in (and family) crisis as a credible source, allowing for the establishment of personal safety, seeing the whole person and paying attention to their real world concerns. The basic principles of crisis care need to be accessed in a timely manner, provided in the least restricted environment, and with peer/family supports. Other specific elements in the article emphasized the need to build in safety and trust, and consider using peer-to-peer response or walk-in crisis centers. It is important to keep in mind that a crisis system that only responds in tandem with law enforcement has limitations and an example of this was offered. It was noted that the education system/schools need to be involved when crisis services are developed in Iowa.

A workgroup member discussed how colleges, including Luther College/Decorah, offer a student course in Mental Health First Aid (MHFA).

Another workgroup member highlighted the need to be sensitive to culture and how one interacts with the children and families as we advance through the phases of core service development. The children and families need to have a comfort level with professionals so they can engage and actively participate in service planning and delivery.

Another article was referenced and discussed. This article, National Disabilities Rights Paper, addressed the use of restraints, debunking myths on the use of seclusion and restraints, and made mention to practices in Iowa. The article highlighted the fact that how a crisis is approached will make all the difference to the children and families. This article is useful to the workgroup as they move forward with system competencies and workforce development needs.

Kappy led the discussion on the draft definition of a System of Care. She noted that this is not a service eligibility definition, but rather a higher level cross-systems whole-health view. The following definition is the finished product of the discussion and the bold texts were the changes from the draft definition.

System of Care for Children in Iowa

A child and family-*driven****, cross-system spectrum of effective, community-based services, supports, policies and processes for children,*** *from birth – young adulthood****, with or at risk for physical****, emotional, behavioral, developmental and social challenges* ***and their families, that is organized into a flexible and coordinated network*** *of resources****, builds meaningful partnerships with families,*** *children, and young adults****, and addresses their cultural and linguistic needs, in order to optimally live, learn, work, and recreate in their communities, and throughout life.***

Workgroup members discussed many aspects about the language in the definition of a System of Care, with an emphasis on how mental health is narrower than behavioral health (which includes substance abuse), a System of Care is not linear, the definition of "youth" in Iowa, and how the Olmstead Plan focuses on the lifespan.

The workgroup reviewed a September 22, 2011 draft of an integrated, cross-age, cross-disability set of **System Outcomes**. It has been reviewed by the IDDD and MH Adult workgroups. The Children's Workgroup members reviewed the document in depth, and workgroup members suggested the following changes as they crosschecked the document with the outcomes the workgroup wants for children and families. The suggestions were:

Page 1: The Iowa Mental Health and Disability Services system should:

- In lieu of using mental illness and disabilities, it was suggested that 'physical, emotional, behavioral, developmental and social challenges' be used.
- It was suggested to strike the word provider, and cite 'Encourage **the use of** innovative thinking and progressive strategies that lead to better results for people.'
- Suggested adding the word '**flexible**' before the word funding.
- Add '**Ensure that children and adults receive the necessary services and supports to achieve their optimal educational potential.'**

Page 2: Individual Outcomes

- It was suggested to add text and punctuation before the word medications in bullet # 9, and include the bolded text, 'People's **treatment, including** medications, are managed effectively and appropriately.'
- Add '**People receive the necessary services and supports to achieve their optimal educational potential.'**

Page 3: Family Outcomes

- Many of the Individual Outcomes could be added to Family Outcomes.
- Language in the Family Outcomes needs to sound more primary as in the Individual Outcomes.

Kappy made reference to the handout from the study presented by Dr. Waldron, with an emphasis on referencing parental support. Dr. Waldron shared language from another document entitled, System of Care Concept and Philosophy Updated from the Training Institutes 2010 that could be used to strengthen language in any/all of the System Outcomes – September 22, 2011. Kappy will bring the recommendations of the Children's Workgroup back to the larger group for consideration.

Before beginning the discussion on identifying Core Services, Kappy and the workgroup discussed likely characteristics of the children and families that are currently out of state and those who are at risk for an out of state placement. The likely characteristics, based on the information the workgroup has gathered to date include:

- Higher level of 'behavioral' problems
- Likely to need multi-system services due to complex and/or coexisting conditions
- More males than females
- Mostly between the ages of 11 – 17
- Higher needs that historically have not been met in state
- Higher incidents of trauma
- Children who have parents with 'high parenting stress'
- Children with parents who don't have anyone to turn to for parenting support

Workgroup members also identified that some youth were sent out of state because centers outside of the state can use interventions (i.e. restraints) that are not permitted for use in Iowa. In addition it is thought that the out of state providers have higher staffing ratios to maintain safety on the units. Kappy acknowledged that while there is no intention of changing the policy about restraints, safety of youth and staff in residential centers is a legitimate concern that needs to be addressed. This includes assuring the use of effective engagement and intervention strategies and use of child and family-centered interventions. Kappy referred to the Alaska report entitled, Alaska Brings the Kids Home, Update and 2 Year Plan, that was shared during the first meeting of the workgroup. Alaska was able to reduce the number of children in residential placement, in state and out of state through the expansion of community-based services. Iowa needs to begin looking at creating services in the community vs. crating services in institutional settings.

In Iowa, many of the children age out of the child welfare system and are transitioned/discharged to family/home. Many of the same children need adult services shortly after discharge. There is a disconnect between the child welfare system and adult services, and often times there is a gap in getting information to professionals who have oversight of adult services.

The workgroup then began the discussion about Core Services. The following Core Services were identified and some cursory descriptors were identified:

1. Care Coordination: Intensive Care planning could include a non-broker model and wrap-around planning; not treatment; 24/7 access; face-to-face, mobile, establishes person-centered goals, and provides continuity across level of care, etc.; while a function of the job, would not be limited to brokering of services.
2. Crisis Stabilization: Lots of ways to look at this. Crisis stabilization models include care in home or out of home, but usually are brief between 24-48 hours and almost always less than 7 days. Could be in home respite. Generally less than 7 days in duration. Could include overnight supports to maintain safety of all family members.
3. Crisis Intervention: Nationally the norm for mobile crisis response is within 60 minutes of the call.
4. Intensive In Home/School Treatment: Necessary to bring children back safely and successfully; begins before the children return to home.
5. Family Peer Support/Navigator: Advocate - need to address housing/employment/school needs.

Further discussion focused on flexible funding streams, need for comprehensive assessments, outcomes and accountability, and how multi-system services would address the needs of children and families. The need for comprehensive assessments is the foundation to determining what a child and/or family needs to be successful and remain at home; discussion also focused on allowing adequate time to do a comprehensive, strength-based assessment and funding a comprehensive assessment. The Community Circle of Care (CCC) in NE Iowa has core principles in the System of Care and it is funded as a system, not on a fee for service basis. The multi-system services would need to show promise in serving the children and families.

While Core Services were being identified, workgroup members were also identifying systemic needs including:

- 24/7 access
- Meaningful access to all LOCs
- Expectation of 'care where you are'
- Rapid response
- Child perceptions of safety is important
- Service portability
- Provider liability
- Family liability ~ referrals to child protection services
- IPART ~ complex cases
- Model fidelity
- Ability to offer doses of treatment (such as very brief PMIC stay)
- Nimble/quick response
- Respite for child/caregiver
- Point of coordination and accountability ~ across levels of care
- Transparency and coordination
- Needs to be family-driven, not family-done
- Need to Harness technology
- Need to talk about access
- Juvenile Justice/Child Welfare risk

NEXT STEPS

Information requested for next meeting: None

Meeting 5 Agenda:

- Expand upon descriptions of Core Services
- Use of SOC model to bring a child home from residential treatment: Walk-through exercise of how two current Iowa SOC programs would approach the challenge
- Build workforce competencies
- Multi-System Readiness
- Report on feedback from the Regional Meetings with 6 themes identified (jail diversion programs, treatment individualized by person, peer support, and housing/transportation/workforce development, adequately funding services, and transition) ~ Joanna Schroeder

MEETING SUMMARY:

- Recapped the meeting minutes from 09/13/11.
- Discussed the findings of the 2010 Iowa Child and Family Household Health Survey on children's mental health.
- Reviewed the common themes from required readings.
- Reviewed the draft definition of System of Care, and crafted a new version.

- Crosschecked the Systems Outcomes with the outcomes the workgroup wants for children and families.
- Identified Core Services and Competency Needs.

PUBLIC COMMENT

Comment: A supervisor from Central Iowa System of Care (CISOC) complimented the workgroup on how they are moving in the right direction in terms of identifying core services for children and their families. Specific comments were made in relationship to the following:

- Care Coordination: This is a hybrid position for brokered vs. non-brokered services. It is a hybrid in that CISOC is going out to the schools and homes to obtain the family voice. The role of the care coordinator is to get the necessary records from previous providers so the family does not have to re-tell their story repeatedly.
- Family Peer Support: This is also part of the care coordinator role to engage families with peers. This provides the family with a voice and advocacy.
- Education: There is a need to help educate parents and assist them in building/honing their advocacy skills. CISCO has partnered with Magellan and have been teaching courses, like Visions for Tomorrow, Wrap-Planning, etc. as a way to connect with families.
- Educational System: This system is often the driving force to get a child into residential placement. Some school will suggest homebound educational services, but this does not always work for the family due to a parent's work schedule. It was recommended that the parent be paid to stay home vs. working; thus, avoiding an out of state placement.

Response: There is a need for modified broker services.

Comment: A parent encouraged the workgroup to consider making changes to how a number of services are identified, such as:

- Use Wellness and Recovery Action Plans vs. Treatment Plans; also look for a return on your investment based on the Wellness and Recovery Action Plan.
- Use Out of State Services language vs. Out of State Placements as a way to be more focused on having the function drive the setting.

She also shared that her son is in an out of state placement at this time. She could not get Consumer Choice Options or Money Follows the Person for her son when he was in the family home. Her son had in home therapy, but the therapist was not reimbursed

the same as a therapist in an outpatient setting. She cited that Iowa needs a Customer Service System for parents to ask questions about the system. She also would like to have parent training vs. pushing advocacy, and mobile crisis units to respond to crisis at school and at home.

Next meeting is Tuesday, October 11, 2011 from 10:00 am – 3;15 pm at United Way of Central Iowa located at 1111 Ninth Street, Des Moines, IA 50314.

For more information:

Handouts and meeting information for each workgroup will be made available at: http://www.dhs.state.ia.us/Partners/MHDSRedesign.html

Website information will be updated regularly and meeting agendas, minutes, and handouts for the six redesign workgroups will be posted there.